

ESORT PPI Workshops – 15 and 17 September 2021

Attendees:

ESORT team: Richard Grieve (Weds), Andrew Hutchings, Claire Snowdon, Silvia Moler Zapata, Paul Charlton, Beth Silver

Clinicians: Ravi Vohra (Friday), Dale Vimalachandran (Friday) and Frank McDermott (Weds)

PPI panelists: Stella, Ollie, Sue, Emma, Katherine, Raj, Debbie (Wednesday); Brian, Fola, Nicola, Sudhir (Friday)

Workshops were held on Wednesday 15 and Friday 17 September. 7 panelists attended on Wednesday and 4 attended on Friday, several joining slightly before the start-time to have an informal conversation. The format was identical for both workshops.

Panelists were provided with bespoke preparatory material in advance via Sway (a) in order to ensure accessibility, particularly because the panel included two visually impaired participants; and b) as we were unable to hold a pre-discussion training session due to the pandemic.

1. Welcome and Housekeeping

Claire opened each workshop by welcoming participants and thanking them for joining. She summarised the four tasks that the panelists would be asked to complete during the session, which included providing feedback on the report's plain English summary. Paul then led the introductions of both the panelists and study team. Beth explained that she would then start recording the session.

2. Reminder of Study Findings

Richard (Weds) and Andrew (Fri) gave an overview of the ESORT study. They reminded the group what the purpose of the ESORT study was, which was considering the benefits of emergency surgery (ES) vs. a 'watching and wait' strategy, which may be planned surgery or management with drugs. Richard/Andrew presented the study's key findings, noting that there was no difference overall for people having ES or non-ES, but outcomes were much worse following ES for frail patients and patients with intestinal obstructions had better outcomes from ES.

Panelists flagged the need for clarity regarding frailty, in particular whether this was linked to age. Regarding intestinal obstruction, panelists commented that there would be a need for greater clarity on what the advice would be for this sub-group.

3. Tasks

Task 1 - Plain English Summary

Claire noted the Plain English Summary (PES) in the pre-read and asked panelists if anything was unclear, missing, unnecessary or needed rephrasing? Panelists commented on the need to reduce sentence length and use bullet points to help clarity. They also supported positioning the findings positively, by referencing the benefits of the different treatment strategies. Some panelists expressed the need to be more explicit in the PES regarding mortality risk and the higher care costs of a longer stay in hospital.

Task 2 - Targeted List

For the second task, Claire asked panelists who should be informed of the study results. Panelists suggested producing leaflets which could be made available to patients and their families, as well as using the ESORT website. There was a discussion about targeting groups that support frail patients,

such as the MS Society and Age Concern. It was agreed that specialist nurses could also be informed, for instance those working in stoma teams working with patients at risk of a future emergency, and those working in A&E who might encounter emergency patients as they enter the hospital system. Frank also noted the importance of advance directives and the importance of people communicating with their GPs. Panelists discussed the importance and relevance of the information from ESORT to informed consent and shared decision-making between patients and doctors, whilst others focused more on using the information to retrospectively understand how surgical decisions were made.

Claire invited panelists to take a short break and undertake the activity detailed in the slides, using the notes document provided.

Task 3 – Important Messages

Claire asked panelists what important messages should the study team be communicating, particularly in order to support shared the decision-making and advance directives discussed previously. Panelists discussed the need to communicate the importance and benefits of alternatives to ES, to ensure that patients do not feel that they are being ‘denied’ surgery. They also expressed the need to understand the process by which decisions were made. Panelists also discussed the impact of COVID, which meant people were less inclined to present at hospital and also necessitated considering different treatment options.

Task 4 – How and when

Paul flagged the concept of easy-read formats as an accessible information standard, using clear language and images. Panelists welcomed the ESORT easy-read document and suggested making the texts available in other languages, and compatible with screen-reading software. They discussed using Twitter, although noted that over 85s and their c.55 year-old children may not be on social media. They also discussed using the ESORT website as a resource for clinicians.

Additional Thoughts

Claire invited panelists to provide any further thoughts on the points covered. Panelists again demonstrated interest in accessing more detail about the results and sought clarification of the meaning of frailty.

4. Next Steps and Future Research

Richard/Andrew mentioned that there was an ESORT-C19 project, funded by the Health Foundation. There would be a PPI translation panel early 2022.

They then flagged the NIHR extension funding available for studies looking at patients with multiple long-term conditions and asked the panel if they agreed this was an important question, what a PPI panel could offer and whether panelists would be interested in joining? Several panelists noted that they would be willing to get involved and supported the study’s proposals. The group discussed the fact that it would be beneficial to bring in others with experience of living with multiple conditions, so the PPI panels were a hybrid of individuals from the ESORT NIHR study and new members.

5. Meeting Close

Paul then closed the meeting by noting the difficulty of having these conversations, which involve revisiting trauma. He thanked the ESORT team for their contributions to the panel.